Complete Summary

GUIDELINE TITLE

Guidelines for Alzheimer's disease management.

BIBLIOGRAPHIC SOURCE(S)

California Workgroup on Guidelines for Alzheimer's Disease Management. Guidelines for Alzheimer's disease management. Los Angeles (CA): Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties; 2002 Jan 1. 52 p. [296 references]

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Alzheimer's disease

GUIDELINE CATEGORY

Evaluation
Management

CLINICAL SPECIALTY

Family Practice
Geriatrics
Internal Medicine

INTENDED USERS

Advanced Practice Nurses
Nurses
Physician Assistants
Physicians
Social Workers

GUIDELINE OBJECTIVE(S)

To serve as a general guide for the ongoing management of people with Alzheimer's disease

TARGET POPULATION

Adults, primarily elderly, with Alzheimer's disease

INTERVENTIONS AND PRACTICES CONSIDERED

1. Assessment of daily function, cognitive status, other medical conditions, and behavioral problems, psychotic symptoms, and depression
2. Regular reassessments
3. Identification of primary caregiver and assessment of support system
4. Assessment of patient's decision-making capacity and identification of surrogate
5. Assessment of patient's and family's cultural values
6. Development and implementation of an ongoing treatment plan with defined goals:
    - Cholinesterase inhibitors
    - Referral to appropriate structured activities
    - Treatment of medical conditions
7. Treatment of behavioral problems and mood disorders:
    - Nonpharmacologic approaches (e.g., environmental modifications, task simplification)
    - Referral to social service agencies or support organizations
    - Medications
8. Education of patient and caregiver
9. Reporting elder abuse and Alzheimer's disease to appropriate state agencies

MAJOR OUTCOMES CONSIDERED

- Physical and mental status changes
- Daily functioning ability
- Quality of life

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The literature review conducted for the 1998 guideline yielded 275 source documents.

An extensive literature review yielded 222 articles published since the 1998 release of the original guideline; these were coded as relevant to content areas and reviewed by the content work groups. The content areas include assessment, treatment, patient and caregiver education, and reporting requirements. The revised guideline and report also focus attention on Alzheimer's disease care concerns of diverse populations.

NUMBER OF SOURCE DOCUMENTS

Original guideline (1998): 275 source documents

2002 update: 222 articles published since the 1998 release of the original guideline

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

The articles reviewed were coded as primary or supplementary by publishing data and content area. The most recent primary articles were chosen as supporting evidence for the guidelines, along with several key seminal articles on Alzheimer's disease care.

The language used throughout the report reflects the strength of the evidence. Articles were graded based on study design and the strength of the conclusions from the study. In the report, these studies are referred to as â œstrongâ evidence (e.g., randomized clinical trial), or â œmoderate.â

METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Executive committee and workgroup meetings were held to establish and choose the most vital guidelines for post-diagnostic assessment, treatment, patient and caregiver education and reporting requirements. Each recommendation is supported by the latest available research findings, expert opinion, and Workgroup consensus. In certain instances the current literature does not provide sufficient evidence-based recommendations, however, expert opinion and Workgroup consensus were used to develop recommendations. This general organization is used for each of the four sections of recommendations.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Original guideline: Draft guidelines covering the four areas (assessment, treatment, patient and caregiver education, and reporting requirements) were sent to 240 external reviewers expert in Alzheimer's disease. 200 responses were received. A final one-page version of the guidelines was written and ratified in a meeting attended by the guideline development participants.

2002 Update: No additional information is provided.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Assessment

Overview

Comprehensive and appropriate treatment plans that meet all patients' needs can only be developed as a result of thorough assessment of the patient, the family, and the home environment. The assessment should address the patient's medical condition, including functional status, cognitive status, other medical conditions, behavioral problems, psychotic symptoms, and depression. The assessment should also address the patient's support system, identify the primary caregiver and the patient's decision-making capacity. The family and caregivers are an important source of information. Physicians should solicit and consider their input in post-diagnostic treatment planning.

Recommendations

Conduct and document an assessment of:

- Daily function, including feeding, bathing, dressing, mobility, toileting, continence and ability to manage finances and medications
- Cognitive status using a reliable and valid instrument (e.g., the Mini-mental Status Exam [MMSE])
- Other medical conditions
- Behavioral problems, psychotic symptoms, or depression

Reassessment should occur every 6 months or more frequently with any sudden decline or behavioral change.

Identify the primary caregiver and assess the adequacy of family and other support systems.

Assess the patient's decision-making capacity and whether a surrogate has been identified.

Caregiver's needs and risks should be assessed and reassessed on a regular basis.

Assess the patient's and family's culture, values, primary language, literacy level and decision-making process.

Treatment

Overview

Ongoing regular medical management of general health (other medical conditions and prevention), in addition to monitoring of cognitive deficits, is essential. Management goals and activities should be based on a solid alliance with the patient and family and thorough psychiatric, neurological, and general medical evaluations of the nature and cause of cognitive deficits and associated non-cognitive symptoms. All evaluations must take into account the effect of cultural practices and beliefs on symptomatology and appropriate treatment options. Ongoing efforts should also include periodic monitoring (a minimum of every 6 months) of the development and evolution of cognitive and non-cognitive symptoms and their response to intervention. It is important for health care professionals to be sensitive to symptoms associated with Alzheimer's disease to facilitate early intervention when unusual or sudden symptoms arise.

Recommendations

Develop and implement an ongoing treatment plan with defined goals. Include:

- Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
- Appropriate treatment of medical conditions
- Referral to adult day services for appropriate structured activities such as exercise and recreation

Treat behavioral problems and mood disorders using:

- Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.
- Referral to social service agencies or support organizations, including the Alzheimer's Association's Safe Return Program for people who wander
- Medications, if clinically indicated and non-pharmacologic approaches prove unsuccessful

Patient and Caregiver Education

Overview

The primary care practitioner should provide information and education about current level of disease and should talk with the patient and family to establish treatment goals. Based upon the agreed upon goals, the primary care practitioner should discuss the expected effects (positive and negative) of intervention and treatment on cognition, mood, and behavior to ensure that the strategy is appropriate to family values and culture. Studies have shown that the education of caregivers increases chances of adherence with treatment. Thus, family and caregivers must become knowledgeable about the care of the patient and fully aware of the changes that might occur as a result of the disease process. It is the role of the primary care practitioner to assist the family caregiver in understanding the patient and patient behaviors, and to provide information on how to access community services. There is moderate evidence to suggest that the most helpful information for the caregiver fro the primary care practitioner is help in managing the day to day activities of Alzheimer's disease caregiving, either via tips/training or encouraging the use of community-based services. The primary care practitioner should also provide information regarding patient rights and advance planning for informed consent, health care surrogates, and/or durable power of attorney.

Recommendations

Discuss the diagnosis, progression, treatment choices and goals of Alzheimer's disease care with the patient and family in a manner consistent with their values, preferences and the patient's abilities.

Refer to support organizations for educational materials on community resources, support groups, legal and financial issues, respite care, future care needs and options. Organizations include:

- Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties , 1-800-660-1993, Web site: www.alzla.org
- Family Caregiver Alliance and Caregiver Resource Centers, 1-800-445-8106, Web site: www.caregiver.org
- A local social service department

Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.

Discuss the intensity of care and end of life care decisions with the person with Alzheimer's disease and the family.

Reporting Requirements

Overview

Primary care practitioners are required by law to report instances of elder abuse as well as the diagnosis of Alzheimer's disease to appropriate agencies. The primary care practitioner can monitor for abuse as well as offer interventions to the patient and the caregivers through medical treatments and referrals to community agencies. Reporting requirements may vary by state; the recommendations below are for the State of California.

Recommendations

Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment) to Adult Protective Services, the local police department, or the appropriate state agency, as required by law.

Driving: Report the diagnosis of Alzheimer's disease to your local health officer (county health department) in accordance with applicable state law.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

Each recommendation is supported by the latest available research findings, expert opinion, and Workgroup consensus.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Minimize effects of Alzheimer's disease on patients' physical and mental status, overall functioning and quality of life.

POTENTIAL HARMS

Medical Treatment of Mild to Moderate Alzheimer's Disease

Cholinesterase Inhibitors:

- Donepezil hydrochloride (Aricept®): Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea (can be reduced when taken with

food). Conflicting evidence regarding a possible drug interaction with cimetidine, theophylline, warfarin and digoxin. Rarely patients experience increased agitation, which subsides after a few weeks.
- Galantamine (Reminyl®): Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea (can be reduced when taken with food). Sleep disturbances commonly associated with other cholinergic treatments do not appear to be a problem with galantamine.
- Rivastigmine tartrate (Exelon®): Mild gastrointestinal symptoms including nausea, vomiting, and diarrhea; headaches, dizziness, fatigue, and malaise.
- Tacrine (Cognex®): Gastrointestinal problems are common. Side effects reduced when taken with food. Drug interaction with theophylline, cimetidine, ametidine. Hepatotoxicity is a problem and should be monitored every other week for 4 to 6 weeks and then every 3 months.

Pharmacologic Treatment of Behavior Disorders

Antipsychotics:

- Atypical: Diminished risk of developing extrapyramidal symptoms and tardive dyskinesia.
- Typical: Associated with significant, often severe, side effects involving the cholinergic, cardiovascular, and extrapyramidal systems. There is also inherent risk of developing irreversible tardive dyskinesia in 50% of elderly after two years of continuous use.

Non-antipsychotics:

- These are to be used with caution in patients with premature ventricular contractions (PVCs); may alter blood counts and liver enzymes; may produce problematic side effects.

Benzodiazepines:

- Regular use can lead to tolerance, addiction, depression, and cognitive impairments. Paradoxical agitation occurs in about 10%. Infrequent, low doses of short half-life agents are least problematic.

Antidepressants

- Tricyclic antidepressants: Hypotensive and anticholinergic side effects; may cause tachycardia; to be used with caution in patients with premature ventricular contractions; sedating.
- Hetero- and noncyclic antidepressants: AM orthostatic hypotension; to be used with caution in patients with premature ventricular contractions.
- Selective serotonin reuptake inhibitors (SSRIs): As a class, typical side effects include sweating, tremors, nervousness, insomnia/somnolence, dizziness, and various gastrointestinal and sexual disturbances.
- Lithium: Elderly are prone to develop lithium neurotoxicity at higher doses.

See also Table 8 titled "Pharmacologic Treatment of Behavior and Mood" in the original guideline document for drug-specific cautions for pharmacologic agents used for treatment of behavior and mood disorders.

CONTRAINDICATIONS

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Cholinesterase inhibitors are contraindicated in patients with bradycardia.

Galantamine (Reminyl®) is contraindicated for patients with hepatic and/or renal impairment.

QUALIFYING STATEMENTS

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- The guideline suggests care management principles and is based on the assumption that a proper diagnosis of Alzheimer's disease has been made using reliable and valid diagnostic techniques.
- Inclusion of a recommended action in this guideline does not necessarily imply that the action should be taken by the primary care practitioner alone; the guideline is intended to cover recommended actions that the primary practitioner may refer to others to address (e.g., a social worker, a community support group, or the Alzheimer's Association).

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

The objective is to increase awareness and use of the "Guidelines for Alzheimer's Disease Management." The strategy includes the development of tools such as a provider checklist, medical record audit form, and clinical pathway. Two tools have already been developed. A "Consumer Fact Sheet" for patients and their families, and a "Quick Reference Guide" for physicians and health care workers, are currently available electronically at the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site. Print copies of these tools are also available through the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties office. The "Quick Reference Guide" can be shared, copied, put into newsletters, or made into pocket guides to facilitate implementation of the guideline. (See the "Companion Documents" field for availability information.)

In addition, the strategy discusses endorsement and distribution by major professional/trade associations, publication of the guidelines in peer reviewed journal, a targeted press release to general media and the recruitment of opinion leaders within each health care organization structure. This implementation strategy was developed by the Center for the Study of Healthcare Provider Behavior (summarized in the report titled "Rand Report: Dissemination and Implementation of the California Guidelines for Alzheimer's Disease

Management"). Copies are available through the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties (see the "Companion Documents" field for availability information).

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

California Workgroup on Guidelines for Alzheimer's Disease Management. Guidelines for Alzheimer's disease management. Los Angeles (CA): Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties; 2002 Jan 1. 52 p. [296 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

1999 Jan 8 (revised 2002 Jan 1)

GUIDELINE DEVELOPER(S)

Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties - Private Nonprofit Organization
California Workgroup on Guidelines for Alzheimer's Disease Management - Independent Expert Panel

SOURCE(S) OF FUNDING

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GUIDELINE COMMITTEE

California Workgroup on Guidelines for Alzheimer's Disease Management, including members of the Workgroup Executive Committee (identified in bold print under "Group Composition")

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Workgroup Members: Mary Alice Cardenas; Ronald Chapman, MD, MPH; Debra Cherry, PhD; Tiffany Chow, MD; Helena Chui, MD; Richard Della Penna, MD; Susan DeMarois; Cordula Dick-Muehlke, PhD; Darby Duke; Edith S. Eddleman-Robinson, LCSW; Elizabeth Edgerly, PhD; Lynn Friss Feinberg, MSW; Patrick Fox, PhD, MSW; Janet Frank, DrPH; Joyce Fukui; Ted Ganiats, MD; Frances Martinez-Goodrich, MSW; Elizabeth Heck, MSW, LCSW; Linda Hewett, PhD; Robert Hierholzer, MD; James T. Howard, MS; Kit Lackey; Daniel A. Lang, MD; Marcia Levy-Rosenstein, MPH, MPA; Katie Maslow, MSW; Dana Miller, MPH; Lydia Missaelides, MHA; Brian Mittman, PhD; Janet Morris, JD; Laura Mosqueda, MD; Carol Motylewski-Link; Ruth Mulnard, RN, DNSc; Cheryl Phillips-Harris, MD; Michelle Plauch, MA; Janet Roberts; Craig Rosen, PhD; Milton Sakamota, MD; Debra Saliba, MD, MPH; Dan Schroepfer; Freddie Sigal-Gidan, PhD; Lynda Taylor, MSW; Laura Trejo, MSG, MPA; Dodie Tyrrell, MA; Ramon Valle, PhD; Barbara Vickrey, MD, MPH; and Sharron Watts, MPA; George Xakellis, Jr., MD, MBA; Josephine Yelder, PhD.

(Members of the Workgroup Executive Committee are identified in bold print.)

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the most current release of the guideline. It updates a previously issued version (Guidelines for Alzheimer's disease management. Los Angeles [CA]: Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties; 1999 Jan 8. 23 p.).

GUIDELINE AVAILABILITY

Electronic copies: Available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site.

Print copies: Available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties, 5900 Wilshire Blvd, Suite 1700, Los Angeles, CA 90036.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Provider checklist for treating a confused elder. Los Angeles (CA): Alzheimer's Association and Related Disorders Association, Inc., 2002. 1 p. Available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site. Click on the "Checklist" link to access the information. Print copies are available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties, 5900 Wilshire Blvd., Suite 1710, Los Angeles, CA 90036.
- For physicians and other health care professionals caring for patients with Alzheimer's disease, a one-page quick reference guide titled "Guidelines for Alzheimer's Disease Management," (Los Angeles [CA]: Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties, 2002. 1 p.) is available. Both national and California-specific documents are available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site. Click on the "California Guidelines" or "National Guidelines" link to access the information. Print copies are available from the Alzheimer's Association of Los Angeles.
- Mittman BS, Saliba MD, Lang DA, Vickrey BG. Rand report: dissemination and implementation of the California Guidelines for Alzheimer's Disease Management. Sepulveda (CA): VA Greater Los Angeles Health Care System, Center for the Study of Healthcare Provider Behavior; 1998 Sep. 49 p. Electronic copies are available from the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site. Click on the "Rand Report" link to access the information.

PATIENT RESOURCES

For patients and their families, a guideline summary and consumer fact sheet titled "Working with Your Doctor When You Suspect Memory Problems" (Los Angeles [CA]: Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties, 2002. 12 p.) is available from the Alzheimer's Association of Los Angeles.

Copies may be obtained electronically at the Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Web site Choose the link titled "Alzheimer's Health Education Initiative (AHEI)."

Print copies are available from the Alzheimer's Association of Los Angeles, 5900 Wilshire Blvd., Suite 1710, Los Angeles, CA 90036.

NGC STATUS

This summary was completed by ECRI on April 14, 1999. The information was verified by the guideline developer on June 11, 1999. The summary was most

recently updated on May 3, 2002. The updated information was verified by the guideline developer as of May 9, 2002.

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